

Tuesday, October 24, 2017
The Honorable Health Policy Committee
124 N. Capitol Avenue
Lansing, MI 48909

Dear Members of the Health Policy Committee,

The first thing I would like to recognize is that the issue at the core of this discussion, developing the best possible educational and interventional infrastructures for children in Michigan who are deaf, deafblind, and hard of hearing, is paramount. I unequivocally agree that the system as it pertains to how we educate our children needs help.

However, after careful study of the strategy outlined in HB5158, there are several issues to be aware of. Let me first begin with what I support in its entirety:

- **Sec. 1705 (2):** Parents and legal guardians are the people who are responsible for their children's well being and it is our responsibility to develop a support system that allows for freedom of choice. Where the status quo clearly falls short in many cases, we must facilitate an environment that leaves room for innovation and options, even if they are not currently available in a school system. Parents must be allowed to, without undue pressure, decide on a strategy that they believe in and receive those chosen services from their school district.
- **Sec. 1705 (4):** I am of the belief that there is no such thing as, "too many resources," for families desperately seeking answers. I fully and happily support the development of an information guidebook that provides as many answers as possible. There are existing resources that can be drawn upon cost-effectively such as the guidebooks developed by Hands & Voices, which are unbiased and geared towards the development of support systems, individualized goals, and collaborative efforts between families and professionals towards shared goals. The University of Michigan also has a wonderful guidebook resource. **My recommended interventional strategy towards the improvement of educational outcomes for children who are deaf, deafblind, or hard of hearing is to ensure that every single school district in the entire state of Michigan is able to provide the services chosen and requested by parents.**
- **Sec. 1705 (4) (E):** The single most important indicator of the educational success of a child who is deaf, deafblind, or hard of hearing is the level of involvement that parents are able to achieve, particularly as language models. In order to reach the critical window of language acquisition, parents need to open the lines of communication as quickly as possible. Whether it's participating in receptive or expressive verbalization practice with auditory aids or learning a visual communication system such as Cued Speech or Sign Language, we need to support parents in that goal as much as they will let us.

Before I continue to my reservations, let me share some context. After I was diagnosed as congenitally profoundly deaf, my parents sought out a way to be able to communicate fully and fluidly in the language of their home, which was English. They recognized the early language acquisition window and the fact that the language that they felt most comfortable modeling for me was the one they were already fluent in, English. After discovering that auditory feedback was not a viable or reliable option for me to gain access to language, they learned about Cued Speech. They learned to cue within two weeks since it is a mode of communication to convey pre-existing languages such as English. Some compare the learning process to that of learning to type. My expressive and receptive English skills were age appropriate by the time I was three years old.

A video of my parents communicating with me and telling their story can be seen here: <https://vimeo.com/62318927>

The trouble began when they first encountered the educational system. At the age of five, I was given language assessments by a Illinois State sanctioned entity, the Low Incidence Cooperative Agreement (LICA). Those assessments confirmed that I was at or above age appropriate level for a hearing child. Our local school district only offered a self-contained Total Communications classroom that utilized Sign Language, which my parents felt was not appropriate because I was already fluent in English via the use of Cued Speech. They asked for me to be mainstreamed with a Cued Speech Transliterator. LICA, again sanctioned by the State of Illinois, advised the school district to reject my parents' request. My parents took the school district to the Illinois Supreme Court (Lachman Vs. Illinois State Board of Education) and because this case was before the enactment of the Individuals with Disabilities Education Act (IDEA), they lost. The Illinois Supreme Court ruled that schools had the right to overrule parents when it came to the educational decisions of their children because they are, "the experts." The original circuit Judge now claims he regrets his ruling in favor of letting the School District choose my educational methodology because he felt compelled to follow the text of the law exactly as it was written at the time.

My parents chose to open a private mainstream Montessori School with both hearing children and children with hearing loss and every child had access to the same language and educational content through spoken and cued English. My parents would not have gone that route had the public school system not failed us and forced us to go to extraordinary measures to pursue the educational strategy that I needed.

That was an example of a State sanctioned educational infrastructure designed to educate children with disabilities in a manner that was geared towards a singular common denominator. This was back when children with disabilities were guided into self-contained classrooms based on what was easiest, not what was most effective or most appropriate for each individual child. Now, we have IDEA and the right for each child and their respective support system to pursue a Free and Appropriate Public Education (FAPE) with an Individualized Education Plan (IEP).

Here are a few of my concerns, but I would like to preface them with a statement that I fully and unequivocally support all educational options, whether they utilize American Sign Language, Listening and Spoken Language, visual access to languages via Cued Speech, or any strategy that a family may see benefit from. My testimonial is not intended to show bias towards any educational preference(s), but rather it is geared towards the development of a system that supports and empowers families rather than pushing them into easy and convenient silos like mine was based on the advice of a seemingly well-intentioned agency that serves at the pleasure of the State.

- **Sec. 1705 (1):** The assessment tools as described in subsection (6) are intended to be used to monitor and track developmental milestones, which are, "derived from existing standardized norms and aligned with existing standards used to meet the requirements of Federal law."
 - If children are being monitored and tracked, what is the intended use of that derived data? What assurances do Michigan citizens have that they will still enjoy the freedom of choice legally afforded to them under IDEA? If state assets are allocated towards a limited array of programs at the expense of others based on publicly available data, how do programs that do not receive those benefits continue to service their consumers based on their choices?
- **Sec. 1705 (4)(D):** I would advise caution on describing the risks of language deprivation to parents because we currently operate in a tense environment with a very diverse range of opinions and interpretations, so the definition of language deprivation varies from person to person. Many people believe that the singular act of not including ASL is language deprivation in and of itself. Other people believe that the act of not providing access to auditory habilitation is language deprivation. For the State to step in and create a single unified definition of language deprivation removes many of the variables that go into a family's choice of interventional strategies. If a law can be interpreted to say that the lack of ASL is language deprivation, families will feel pressured by the State. The same is true if language deprivation is defined as the lack of

auditory habilitation. While we must work to inform parents as thoroughly as possible, it is my recommendation that parents receive that information from their interventional support systems in the course of normal order rather than under a State sanctioned apparatus that carries legal weight and pressure.

- **Sec 1705 (8):** I find this section to be extraordinarily dangerous because according to this section, a third party is able to legally put into a child's IEP, without the parent or guardian's permission, a subjective notation that indicates a failure to demonstrate reasonable progress based on the assessments and standards developed by a limited number of people on the Advisory Committee, which is a product that we do not have at this time. This can influence the decision making process of an educational institution because from my perspective, they are more likely to play it safe and this puts the onus on the school district to make the IEP process *innumerable more difficult* and it threatens to put administrators at odds with the primary decision makers, parents. There will be an extraordinary number of cases where an administration decides to push for a change in educational strategy because they are under the impression that doing so will earn them higher performances when that course of action is nowhere close to well defined or clearly understood and it threatens to throw a family's efforts completely off kilter, which defeats the purpose of our shared mission.
- **Sec. 1705 (9) and Sec. 1705 (10):** If there are pre-existing standardized norms at the Federal level, what is the purpose of convening an advisory committee to pick and choose assessment tools, recommended developmental milestones, and suggested methods for monitoring and reporting outcomes? Who are those reports geared towards and to what end? I am only able to support these assessments and reports if they are designed specifically for the use of the family and their support system. If reporting is made too easily available, identities can be derived from limited data sets because there would be only hundreds of children subject to assessment and basic identifiers can jeopardize individual privacies, which is a violation of HIPAA.

Furthermore, incomplete contextual data such as age of intervention, number of additional disabilities, whether one or multiple strategies are being utilized, and so on are all contributing factors to each child's individual performance and growth that provide critical context for any decision making process. Each of these factors affects outcomes in numerous ways so the larger the sample size becomes, the more context is lost, leading to incomplete or insufficient data that can be used for decision making. For example, a deaf child who is adopted from a non English-speaking country would start their English language acquisition process at whatever age they arrive in this country but their results would apparently be included in this reporting without that information. This is *the* critical point behind the reasoning for prioritizing individualized educational strategies over State level programmatic interventions. I fear that it is not possible to comply with subsection (18) when this data is reduced to State levels.

My recommended course of action to combat language deprivation is to develop or expand resources that increase the accessibility and efficiency of language and communications modality learning opportunities across the board for families, professionals, and other support systems. Under that course of action, there is no requirement for an advisory committee in order to provide resources for all options, regardless of geography or personal beliefs and it is implementable immediately.

All of this being said, I support the Deaf Child's Bill of Rights, also referred to as 2017 Michigan House Bill 5159, in its entirety.

Thank you, esteemed committee members, for the opportunity to offer feedback.

Sincerely,

Benjamin Lachman
West Bloomfield Township, MI

